# HHT and Insurance:
# Overview, resources, and out-of-network concerns

Families with HHT have many considerations in regard to health insurance coverage. This article will provide a brief overview of the broad spectrum of topics including obtaining coverage, eligibility, scope of benefits, out-of-pocket costs, and authorizations, with special attention on out-of-network considerations. It is no wonder that families with genetic disorders find themselves not only focusing on the many aspects of diagnosing and treating their medical condition, but also devoting considerable time, attention, and often anxiety to the requirements of health insurance coverage. To complicate matters further, various family members are often covered under different plans depending on employment situation, age, income, and level of disability.

**Step 1: Obtaining health insurance coverage**

Generally, the first concern is obtaining health insurance coverage through group plans, individual policies, high risk state health plans, Medicare, Medicare disability or Medicare supplements, Medicaid, or Children's Health Insurance Plans (CHIP). A couple barriers to obtaining insurance are cost, and denials for medical history (including genetic conditions). Some persons consider avoiding the diagnoses or treatment of a suspected health condition, dangerously gambling that it could affect future ability to get insurance. However, the mere presence of symptoms or familial conditions may affect a health insurance application as much as, or more than prior treatment. http://www.statehealthfacts.org/ is a great on-line resource with information on qualifying for health insurance programs, by state.

**Step 2: Eligibility and health insurance**

Second to obtaining insurance coverage is maintaining eligibility with proof of continuous coverage, COBRA coverage, and pre-existing benefit exclusions considerations. Beware that if at any time there is a lapse in insurance coverage, a new insurer can impose pre-existing condition benefit exclusions, meaning there may be no coverage for prior conditions until up to a 12-18 months have passed with no treatment for those conditions. Generally these exclusions cannot be applied if a person has proof of continuous coverage. This "certificate" of coverage can be obtained from an existing insurance company anytime a person changes employers or insurance companies. It is very important to try to find a way to pay monthly insurance premiums through COBRA whenever changing jobs. Sometimes state agencies will assist with COBRA payments rather than pay for direct medical care.

**Step 3: Insurance benefits**

Thirdly, if insurance eligibility is established, attention is needed to the specifics of the benefit plan. Often times there is a trade-off between lower premiums but significant benefit reduction. Caution has most recently been raised with group health plans offering reduced benefits at annual re-enrollment in exchange for no increase in monthly premiums. "Buyer beware" remains a good credo, as some companies offer drastic benefit deficiencies in basic medical coverage for "lower" monthly premiums. Consumers may assume the benefit coverage is average, when in fact it may not cover hospitalization or other basic needs. Each state has an insurance ombudsman's office that can provide information about insurance companies and state-specific benefit considerations. Check the state government pages of your phone directory for a department or division of insurance.

**Step 4: Out-of-pocket costs**

Fourth, if benefit coverage is satisfactory, there remains various provisions that determine out-of-pocket costs, including level of deductible, co-insurance levels, co-pays for office visits and medications, and disproportionate benefits for out-of-network coverage. The past few years have seen ever-increasing out-of-pocket cost sharing for prescription medications, and shifting of prescription medication to over-

the-counter medications paid for entirely by the consumer. Some of this benefit reduction is in response to heavier consumer use of brand-name medication secondary to demand generated from commercial advertising.

When choosing from benefit plans, families with HHT should be especially on guard to "PPO" or preferred provider managed care plans with full benefits applicable to a select local panel of physicians and hospitals only. PPO plans restrict choice by having no provision for "out-of-network" care for specialty HHT centers, requiring the patient to pay 20-40% of billed charges "out-of-pocket."

**Step 5: Pre-authorization for specialty services**

And finally, even with eligible coverage, benefits, and reasonable out-of-pocket costs, there can be authorization requirements for specialized services or "out-of-network" services, which can lead to a series of requests and appeals. Some very good, easy-to-use online resources covering this and other insurance topics, is found at http://www.statehealthfacts.org/ and http://www.kff.org/consumerguide/index.cfm (an excellent consumer guide to seeking approval and appealing to insurance companies for needed services).

To request "out of network" services at an HHT center, it is important to emphasize the cost-effectiveness of a visit to a center where unnecessary or ineffective tests and treatments will be avoided, and appropriate care will be obtained. Most often, insurance companies will require a local physician to write a letter of referral. HHT centers can often assist by providing information about their specialty services. The Cure HHT website at http://www.curehht.org has invaluable, updated reference information for medical professionals when an insurance request is required.

**HHT Centers of Excellence and "out-of-network" insurance considerations**

Specific information regarding insurance out-of-network coverage is important to families with HHT who wish to access HHT Centers of excellence for efficient and expert care. As almost all families with HHT will relate, many top-notch physicians and medical centers know little or nothing about proper HHT management. To seek care at an HHT Center, there is a step-wise approach to verifying insurance coverage. Once health insurance coverage and eligibility are established, there are a couple of matters to assure when seeking care out-of-network. Several types of health insurance coverage limit choice.

State-sponsored coverage may have provisions to keep care within the state. Private insurance that is either "managed care" or "PPO" (preferred provider) may also restrict care to a limited group of hospitals and physicians.

There are two primary ways to limit use of centers of excellence. One method, regardless of the reason or necessity, has limited benefits for care from providers not on a specific list-usually meaning the patient pays a significantly larger proportion of the bill "out-of-pocket." For example, the PPO or managed care plan may have negotiated discounted reimbursement with a limited group of general and specialty physicians and local hospitals. Any time any other provider is used, no matter the need, the patient may be required to pay 20-40% of the billed charges, whereas the "in-network" benefit may only require the patient to pay (co-pay or co-insurance) up to 20% of charges. In addition, the deductible often doubles when service is obtained anywhere but from the contracted list of physicians and hospitals. The purpose of this method is for the insurance company to pay less to both contracted and "out-of-network" health care providers in order to offset rising costs of health care. Physicians and hospitals who do not wish to lose patients by not being on the insurance payor's list, may agree to this type of contract with an insurance company. Unfortunately this method is rigid and does not take into consideration that the total cost of HHT care could actually be much lower at an HHT center since protocols are much better defined and unnecessary testing or ineffective treatment can be avoided.

Persons with HHT should be very cautious when opting for PPO plans when they have a choice of paying a slightly higher monthly premium for a plan with benefits that do not restrict "out-of-network" care.

The second common method of limiting care to specialty centers, is requiring pre-authorization to prove medical necessity. With this method, the insurance may pay for services at the same benefit level as "in-network," if deemed to be medically necessary. It is important for HHT families to be aware of the typical method to request and appeal for medical necessity. It is generally accepted that a patient needing out-of-network care will contact the insurance company's customer service to indicate that service is planned. Very often, it is required that an "in-network" family practice or specialty physician make a referral to an HHT center for the patient, and document this referral in writing in the form of a request to the Medical Director or medical services division of the health insurance plan. It is possible the HHT centers could assist the patient's general doctor by providing specific information about the need for an HHT center visit. It is important for the patient to provide their family doctor with information about the HHT centers in order for the request to be adequate from an insurance reviewer's standpoint.

Once the written request is received, most insurance companies abide by industry standards to provide a response in a timely manner.

If the insurance company were to deny a request, a second review or appeal process is available to the patient. At this point, if either referring or center physicians feel more information could be provided to the original request, it may be beneficial to restate the request in writing. It is important to follow instructions in the individual's benefit plan for making requests or appeals. If however a thorough request with supporting documents were made, many persons find it most helpful to proceed directly with legal assistance in writing a request for second internal or external review or appeal. Because persons with legal expertise in health insurance requests are familiar with the significant variation between state law and how that law applies to specific types of employer group insurance, these legal-assisted second requests and appeals tend to be more effective than patients attempting to handle adverse decisions independently. Another option for resolving disputes with a health plan is to contact the state's department of health insurance, asking for an ombudsman to explain external review options for negative health insurance decisions.

The following are excellent sources of information for the broad spectrum of health insurance topics including obtaining coverage, eligibility, scope of benefits, out-of-pocket costs, and authorizations.

Best of all, the site below is designed to be specific to each state of residence.
Especially helpful are checklists for diagnosing your health care coverage, and checklist for appealing to your health plan.

**Online resources**
http://www.statehealthfacts.org/ Gives a state-by-state map to click for information.
Insurance programs for low-income. Coverage including Medicaid and the State Children's Health Insurance Program (SCHIP). Includes topics such as enrollment, eligibility requirements, managed care participation, spending and federal matching amounts, and enrollment practices.

http://www.kff.org/consumerguide/index.cfm A primer on Medicaid's role as the major provider of health coverage for non-elderly persons with disabilities and on the policy challenges that lie ahead, also providing short profiles of people with disabilities from across the country. An issue paper describing the medically needy option to qualify for Medicaid coverage, describing how it works for people with disabilities and highlighting some key issues surrounding the program.

http://www.kff.org/medicaid/4027.cfm This issue paper describes the medically needy option to qualify for Medicaid coverage, describes how it works for people with disabilities; the elderly, and low-income families; and highlights some key issues surrounding the program. Included in the paper are hypothetical examples of ways in which individuals can qualify for Medicaid as medically needy.

http://www.statehealthfacts.org/ to see what each state offers for high risk insurance.
High risk pools and high risk pool enrollment. Gives a state-by-state map to click for information. The direct address is: http://www.statehealthfacts.org/cgi-in/healthfacts.cgi?action=compare&category=Managed+Care+%26+Health+Insurance&subcategory=State+Sponsored+High+Risk+Pools&topic=High+Risk+Pools

http://www.kff.org/medicaid/4096-index.cfm A new survey of people with permanent mental and/or physical disabilities explores their health-care experiences and challenges in accessing and paying for care. http://www.kff.org/medicare/disabilities.cfm

http://www.statehealthfacts.org/ Managed care insurance

Excerpts from the above on-line resources
http://www.statehealthfacts.org/
http://www.kff.org/consumerguide/index.cfm

**CHECKLIST FOR DIAGNOSING YOUR COVERAGE**
Knowing your coverage will help avoid misunderstandings. Review your plan documents and complete the following worksheet to (1) make sure you understand your coverage and (2) have the necessary information ready in a convenient place when you need to arrange care.

My insurance coverage is through:
- [ ] My employer -- check if:
  - [ ] my plan is an insured plan (subject to state insurance laws)
  - [ ] my plan is a self-funded plan (NOT subject to state insurance laws)
- [ ] An individually purchased policy
- [ ] A group affiliation policy (such as through a civic or educational organization)
- [ ] Other: _____

My insurance plan is a:
- [ ] Health maintenance organization (HMO)
  An HMO typically requires all your care to be arranged and approved through your primary-care physician. Providers (hospitals, doctors, and therapists) must be part of the HMO network.
- [ ] Point-of-service plan (POS)
  A POS plan is an HMO that allows you to obtain some services from providers (hospitals, doctors, and therapists) that are not part of the HMO network. Care received outside the network is usually subject to different payment rules.
- [ ] Preferred provider organization (PPO)
  A PPO plan allows you to use any providers (hospitals, doctors, and therapists) that you want, but you will pay less if you use providers that are part of the PPO network.

Plan number to call if you have a problem: _____
My primary-care physician is: _____
Physician's phone number: _____

I need a referral from my primary-care physician for:

[ ] Lab and x-ray tests
[ ] Gynecologist (for well-woman exam)
[ ] Gynecologist (for other concerns)
[ ] Pediatrician
[ ] Other specialist visits
[ ] Surgery
[ ] Other: _____

My primary-care physician has the following requirements for obtaining referrals:

[ ] Requires an office visit
[ ] Requires _____ days advance notice
[ ] Other: _____

My primary-care physician can refer me to specialists who:

[ ] are part of his or her group practice
[ ] are on the health plan network list
[ ] are outside of the health plan network only if there are no similar specialists within the network
[ ] are outside of the health plan network
[ ] I do not need a referral from my primary-care physician

I have reviewed the Exclusions and Limitations section in my Evidence of Coverage. My insurance will not pay for, or limits, the following services:

[ ] _____
[ ] _____
[ ] _____
[ ] _____
[ ] _____

My plan will cover services at the following hospitals:

_____
_____
_____

What should I do if I need care while I am out of my plan's service area?

For non-urgent care: _____
phone: _____
In an urgent situation: _____
phone: _____
In an emergency: _____
phone: _____

***If you have a POS or PPO plan:***

Although I can use out-of-network doctors for most services, I cannot use out-of-network doctors for the following services:

[ ] Mental health
[ ] Substance abuse
[ ] Other: _____

[ ] There is a maximum amount that can be spent on out-of-network doctors.
[ ] Annual limit $ _____
[ ] Lifetime limit $ _____

If I use out-of-network providers, I will pay a $_____ annual deductible and _____% coinsurance for charges exceeding the deductible.

**CHECKLIST FOR APPEALING TO YOUR HEALTH PLAN**

Who to call: _____

Where to write:

_____

_____

_____

When will you receive a response? (List the time periods at each level for your health plan)
1st level _____
2nd level _____

Note: The federal regulation applicable to employer-sponsored health plans provides that a health plan cannot require more than two levels of appeals, and that if two levels are used, both must be completed within the response times permitted by the regulation.

**1. Patients' rights**

Direct access to providers and standing referrals to specialists. Many health plans require patients to get a referral from their primary care doctor before going to a specialist or before receiving certain services. If you have a health plan such as a POS or PPO that allows you to go to doctors or hospitals that are not part of its network, be aware that the amount the plan is willing to pay for the services you receive may be less than what the doctor or hospital bills. Health plans have no control over charges made by out-of network doctors or hospitals. If the out-of-network provider charges more than what the health plan claims is reasonable, you will have to pay the difference plus any coinsurance. For example, POS or PPO plans usually require you to pay coinsurance (often 20 or 30 percent or more) of their "allowable charge" for services given by providers who are not part of the network. Suppose your out-of-network coinsurance percentage is 20 percent. If the doctor charges $100 for a service and your health plan's allowable charge for that service is only $80, you will pay the $20 difference plus 20 percent of the $80 allowable charge, for a total of $36. Obviously, for complicated procedures and treatments these out-of-network charges add up.

**2. Employer-Sponsored Coverage**
Most people with private insurance are covered by an employer-sponsored health plan. An employer-sponsored health plan is one that you or a family member enrolls in through work and to which the employer makes a contribution for the cost of coverage. If you are enrolled in this type of health plan, you have a right under federal regulations to appeal disagreements about benefits through the plan's internal appeals process. Whether you have additional rights under state law will depend on whether the health plan is insured or self-funded. This is because a federal law, called the Employee Retirement Income Security Act, or ERISA, prevents states from applying their external review laws to employer-sponsored health plans that are self-funded. A health plan is "self-funded" if the employer pays for the costs of health care directly rather than purchasing insurance for its employees.

It can be a challenge for consumers to find out if their health plan is insured or self-funded. You may think your coverage is from a health insurance company like CIGNA or Aetna, but if you work for a large employer, those insurance companies may not actually be insuring you. Instead, they may simply process the claims as a "third-party administrator" for your employer's self-funded plan. To find out whether your employer-sponsored plan is self-funded, first ask the person who administers the benefits where you work. You also can look in the Summary Plan Description that you received from your employer when you enrolled, but often the language is ambiguous on this issue. If you can't find out from your employer or the Summary Plan Description, you can contact the U.S. Department of Labor's regional office nearest to you.

If you are enrolled in an employer-sponsored health plan that is insured, you usually have rights under federal and state laws if you have a dispute with your health plan. Although ERISA also prevents some state laws from applying to insured employer-sponsored health plans, a recent U.S. Supreme Court case found that a state could apply its external review law to a claim dispute involving an insured employer-sponsored health plan. Although this area of law remains somewhat unsettled, consumers should assume that your state's laws apply unless a court says that they do not. If you are enrolled in an employer-sponsored health plan that is self-funded, state laws that provide for internal or external review of health plan disputes will not apply to your plan. However, your health plan must follow a recent federal regulation effective January 1, 2003 for internal plan claims procedure and review of disputed claims.

**3. Individually Purchased Coverage**
If you purchased insurance directly from a health plan (your employer does not provide coverage or contribute to its cost), you need to look at the laws of your state to determine if you have the right to appeal a dispute over benefits using the plan's internal procedures or your state's external review organization. Most states have laws that provide for internal and external review of disputes over coverage you purchase as an individual.

**4. Continuation of coverage**
http://www.statehealthfacts.org/, http://www.kff.org/consumerguide/ or the health section of the Consumers Union website at http://www.consumersunion.org.

**5. Internal review and External review**
With the vast majority of Americans getting their health care through some form of managed care plan, understanding those plans and how to resolve disputes is critical. Today, 40 states plus the District of Columbia have legislated procedures for resolving disputes outside the health plan through "external review" systems, yet studies show these systems are not well utilized.

Disputes with health plans arise over whether services are covered, which treatments should be followed, which providers should be used, how much a service should cost, difficulties dealing with providers, or even billing and administrative mistakes. In most cases, your health plan will have an established appeals process to handle these disagreements. A recent federal regulation effective January 1, 2003 establishes procedures and timelines for claims disputes between consumers and employer-sponsored health plans (both insured and self-funded). Most states have their own rules about how a health plan's internal appeal procedure must be structured. Even if you are eligible to use your state's external grievance procedure, you will usually have to finish your health plan's internal appeal process first, so it is important to learn how your plan's internal process works. Health plans may have different appeals processes for different types of disputes, depending on the nature of the disagreement. For example, a health plan may have a different process for resolving a complaint about appointment times than for a complaint involving a denial of a benefit or a refusal to authorize a medical procedure. Health plans may also have expedited processes to deal with requests for medical services that your doctor feels are urgent. The federal regulation requires employer-sponsored health plans to handle appeals for urgent care claims as soon as possible, but definitely within 72 hours. You need to tell your health plan how urgent your situation is when you first communicate with your plan. The federal regulation also sets up other requirements for employer-sponsored health plan appeals, such as allowing you to submit comments or other evidence to support your case, and requiring health plans to provide you access to the documents used to determine whether or not you have coverage for the services in dispute. Health plans cannot require more than two levels of review for denied claims, cannot charge a fee for the review, and must allow participants 180 days to file an appeal.

**PREPARING AN INFORMAL APPEAL**

When you have a disagreement with your health plan, your first step is to contact the plan's customer relations department. Although many disagreements will be solved at this level, this may be just the first step in a lengthy process. Start your record-keeping immediately. Assemble a file containing any paperwork you already have (such as bills or physician information) and keep a log of every telephone call you make to the plan. Be sure to record the date and the name of the person you talk to and take notes about your conversation. Before hanging up, find out what will happen next and when it will happen. For example, if the representative says he or she will have to find out some information and get back to you, ask when you can reasonably expect a reply. Mark that date in your notes and on your calendar. If you don't hear from the plan by that date, it's time for another phone call.

**PREPARING A FORMAL APPEAL**

If your attempts to deal with the health plan informally are not successful, you will have to file a formal appeal. Health plan procedures vary, but all will require details submitted in writing. Some plans allow you to initiate the appeal on the telephone, but then will ask you to complete a form and submit it before the process can continue. If your plan does not provide an appeal form, consult your Summary Plan Description or the Evidence of Coverage for a description of the appeal process. Look for specific information the plan needs to process your complaint. Be sure to provide answers to all questions. You don't want to add to the delay by forgetting to supply crucial information.

Expect to provide the following information in your written complaint:

- Your name, address, telephone number
- Your insurance plan number or group code and member identification number or Social Security number
- Your provider's name
- Description of the service or procedure that you want to have covered
- Information supporting why the service should be covered
- Recommendations and referrals from your doctor regarding why the treatment or procedure should be covered

- References to the sections of the Evidence of Coverage that apply to your situation
- You may have to file your grievance within a specified time period; it is vital that you do so. For example, the health plan may say it must receive your appeal within one year of the date of treatment or within 60 days of the date the plan tells you it is denying your claim, whichever comes first. Employer-sponsored health plans must allow you at least 180 days to file an appeal.

**HEALTH PLAN REVIEW**

Once the plan receives your written grievance, it will investigate the complaint and make a determination setting out what the plan is willing to do. This procedure goes by different names at different health plans; it may be called an internal review, a level I appeal, or a desk review. The key feature is that this is the first step in the formal plan appeal process.

At this level of review, you may or may not have further contact with the health plan. Some plans allow for informal discussions or consultations between the person making the complaint and the person who is reviewing it. Other plans will review the documentation for your case and notify you only after making a decision. Note that the federal regulation applicable to employer-sponsored health plans provides consumers with the right to present written comments, documents, records, and other evidence to the health plan for consideration in the appeal process.

Response times vary from plan to plan depending on the type of complaint. The plan will usually act more quickly if the service has not been provided, or if the patient is already in the hospital, than if the service has already been given. Some health plans, for example, say that they handle the first level of reviews within one business day for services not yet provided, but others may take longer. Billing and administrative disputes may be handled differently from those involving payment for services. Note that the federal regulation applicable to employer-sponsored health plans sets maximum response times for different types of appeals: 30 days if the service has not yet been provided, 60 days if it has been provided. State law also may establish response times for appeals. If your appeal involves an urgent need for care, make that clear to the health plan so the health plan can expedite your appeal.

If you do not agree with the results of the initial investigation, most plans allow you to appeal the decision to a panel of individuals who were not involved in the initial decision. In some cases you will be asked to appear at a hearing to discuss your case; in others you will not. Each health plan has its own requirements for the composition of the review panel. It may include physicians, consumers, or sometimes representatives of the health plan.

If your plan is subject to state external review requirements, the health plan will usually notify you that it has denied your appeal and give instructions on how to file for an external appeal.

**ARBITRATION**

Your employer-sponsored health plan may require that you enter into mandatory non-binding arbitration as part of the internal review process. Arbitration is a process in which a dispute is resolved by impartial individuals. The arbitration must follow the same federal rules that apply to any internal appeal. In addition, you are allowed to challenge the arbitrator's decision, and may take your dispute to court.

In addition, your employer-sponsored plan may offer voluntary arbitration after one or two levels of internal review. Submitting your dispute to arbitration is optional, and federal law requires that your decision to use or not use this alternative does not affect your rights to any other benefits. If you decide not to use voluntary arbitration, your health plan cannot use this against you in subsequent appeals.

## GETTING AN INDEPENDENT OPINION

### EXTERNAL REVIEW IN YOUR STATE

Most states have external review programs, but the details of administering these programs vary considerably. External review programs often differ in the types of disputes that are eligible for appeal, the process used to resolve the appeal, and the time limits imposed at each step of the process. This section describes the variations found in states' external review programs. Consult the state-by-state tables in Section 4 of this Guide to learn specific requirements for your state and who to contact for further information.

### WHO CAN APPEAL

In most states, state external review requirements apply to all types of health plans. In other states, they apply only to managed care plans (such as HMOs, PPOs, or POS plans), or just to HMOs.

If you are covered by an employer-sponsored plan, you typically can use your state's external review program if your health plan is an insured employer-sponsored plan or a private plan that you have purchased on your own. As we have noted, state external review laws do not apply to employer-sponsored health plans that are self-insured, so if you are in a self-insured or other plan exempted by ERISA from state law, you cannot use your state's external review procedure. At this time, your only recourse is to sue in court. State external review programs also do not apply to Medicare and Medicaid beneficiaries. If you are a Medicare beneficiary, you must follow the Medicare external review process described in your Medicare Handbook. If you are a Medicaid beneficiary, you have the right to a Fair Hearing. Your state or local Medicaid Office can tell you more about the procedure.

In most states, you can give someone else written authorization to appeal for you. In many of the states, your provider may appeal on your behalf with your written authorization.

### WHAT TYPES OF PROBLEMS YOU CAN APPEAL

Most state insurance departments will review your request to be sure that it is eligible for external review before sending it on to an external reviewer. Most states require that the issue at stake involve "medical necessity." That means that you and your doctor must believe a particular procedure, treatment, or pharmaceutical is essential for your health and recovery. Health plans, for a variety of reasons, may disagree. For example, a health plan may believe a particular treatment is ineffective for your condition or is unproven, so it will not pay for it.

Sometimes you and your doctor will want a treatment that could be considered experimental or investigational, but your health plan will not cover the cost. Most states will allow you to submit this type of dispute to external review. Often this kind of disagreement stems from the coverage that your employer has purchased. Many employers do not want their policies to cover experimental or investigational treatments, and their policies explicitly exclude them. Whether or not you can request external review for disputes regarding experimental or investigational treatments depends on your state. Many states explicitly exclude disputes over coverage issues such as experimental treatments. Other states allow denials of coverage for treatments your health plan says are experimental or investigational may be submitted for external review. And a few states do not clearly address the issue and may or may not accept your request for external review. Check the descriptions of state regulations in Section 4 of this Guide for details regarding your state.

Several states require that your dispute involve a minimum amount of money, usually from $100 to $500. In other states, your right to appeal a claim is not limited by the amount of money involved.

**WHEN YOU CAN APPEAL**

If you have a dispute over whether your health plan will pay for a particular treatment, you may have to proceed with treatment before knowing if the plan will pay for it. In many states, you will be able to submit your dispute for external review even if the services have been provided; in others you may submit your case only if services have not been provided.

Most states require you to complete all of the steps in your plan's internal appeals procedure before requesting external review. Some states specify time limits for the internal review, and some allow you to file for external review if you have not received a response within the required time. At least one state, New Mexico, allows you to file for external review at the same time you appeal to the health plan if your case is an emergency.

If you have completed all steps in the internal appeals process, and you have not won your case, you will receive a notice of "adverse determination" or "adverse decision" from your health plan, along with instructions on how to file with the state for external review. You usually must file within a specified period, say 30 to 90 days, after receiving the adverse determination in order to be eligible for external review.

If a delay in receiving services will cause you serious harm, most states have what is called an "expedited review" which will give you a decision in a much shorter period, usually 24 to 72 hours. Your provider must certify that the needed care is an emergency, and sometimes the state agency must agree.

**HOW TO APPEAL**

Every state has a different procedure for handling external reviews. You will usually receive instructions for filing an external appeal when your internal appeal is denied by your health plan. In some states, you will begin the external appeal by contacting your health plan again. Others require that you contact your state's department of insurance or other state agency to initiate your appeal.

The actual review may be performed by the state agency itself or through an independent review organization hired by the state or selected by the plan. Usually you do not have to pay for such reviews, though some states charge a nominal amount, usually $25 to $50.

Although some states schedule a hearing and allow you to speak directly with the reviewer, most do not. In many states, it is not clear whether either you or your health plan must accept the decision made by external review, or whether you can appeal through the court system.

**STATE-BY-STATE EXTERNAL REVIEW PROGRAMS**

This section provides tables with information about the external appeal processes available in each state. Where pertinent, information about the internal appeal process is also provided. Follow the procedures for your state, which were current as of August 2002. For more information, call the state agency or access the state web site listed at the bottom of the page. If your state does not have an external review program, check with your health plan about its internal appeal requirements or with the Department of Labor about filing an appeal if your plan is a self-insured employer-sponsored plan.
http://www.kff.org/consumerguide/states.cfm

A *Consumer Guide to Handling Disputes With Your Private or Employer Health Plan*
was developed by the Kaiser Family Foundation and Consumers Union, the publisher of Consumer Reports magazine provides practical information to plan enrollees who are seeking a way to resolve a dispute with their health plan or to better understand their coverage before a problem arises.

"Disputes with health plans range from simple communication problems to delays or denial of coverage or care, and it is critical that consumers have the tools they need to navigate the dispute resolution process."

1. Know your coverage - If your employer provides health care coverage, you probably received a Summary Plan Description when you first signed up. It will discuss covered services, limits on benefits, and your payment amounts in language that is easy to understand. Or, you can discuss exclusions with your human resources manager at work.
2. You may also need pre-authorization by the health plan for some services such as surgeries. Often the doctor's office will contact your health plan to obtain this pre-authorization. For some plans you may need to contact the health plan directly. A phone call to the health plan in advance of a surgery or out-of-network service to verify that all authorizations are in order is far easier than finding out that approval has not been granted or paperwork is missing when you show up at a center.
3. Appealing through your plan, preparing for: Informal appeal, Formal appeal, health plan review, arbitration
4. External review - who, what, when, how, state-by-state

**The following is a template request letter for services at an HHT Center of Excellence.**

(Date)

(Patient or referring physician name)
(Patient or referring physician address)

(Insurance company name)
(Insurance company address)
Attn: (Insurance company Medical Director name)

RE: Member (name) (member ID#)

Dear Dr. (Medical Director name):

This request is for medical necessity authorization for the above-named member to receive out-of-network services for a consultation visit at a center of excellence for a family genetic disorder, Hereditary Hemorrhagic Telangiectasia (HHT). An appointment has been scheduled for (patient name) on (date) at the (HHT Center of Excellence) with (physician's name).

HHT is an autosomal dominant disorder. Affected individuals have a 50% chance of passing the gene to each of their offspring. Penetrance is high, but age-dependent, and expression is highly variable both between and within affected families. Therefore, one cannot rely on the presence or absence of clinical features of HHT to determine the status of at-risk individuals from affected families. This is especially true in young children.

Accurate diagnosis is desirable because affected individuals can benefit from screening and treatment regimens aimed at preventing some of the most serious complications associated with HHT. Besides skin and mucosal lesions, approximately 40% of individuals with HHT have pulmonary artery-vein malformations (AVMs) and about 15% have cerebral AVMs. These AVMs are often silent. A pulmonary AVM can lead to embolic stroke or brain abscess (the result of right to left shunting/loss of filter function in the lungs). Individuals with a cerebral AVM are at increased risk for cerebral hemorrhage. These events can occur suddenly in people who previously displayed no obvious clinical symptoms of an AVM. Pulmonary and cerebral AVMs are usually treatable at low risk if detected before a catastrophic event. Patients with HHT may have other unrecognized problems, such as bleeding from telangiectases in the gastrointestinal tract and/or heart failure due to AVMs in the liver.

While there are differences in opinion concerning the exact timing and methodology for screening in HHT it is generally accepted that screening for lung and brain AVM's should take place during childhood. Since children often do not have outward signs of the condition, but can suffer serious complications from untreated AVMs, current recommendations are to screen all children of an affected parent. Many experts recommend screening for brain AVMs in infancy, which involves an MRI with sedation.

- Because one cannot rely on the presence or absence of clinical features of HHT to determine the status of at-risk individuals from affected families; and,
- Because accurate diagnosis achieved through screening and analysis of screening findings by someone with expertise in HHT is necessary in order for affected individuals to benefit from

treatment regimens aimed at preventing some of the most serious complications associated with HHT; and,

- Because of the vascular nature of HHT affecting multi-organ systems, the condition lends itself to evaluation using a center of excellence model involving a multi-disciplinary approach coordinated by a lead physician with expertise in HHT rapidly-evolving diagnosis and treatment modalities appropriate to HHT;
- Therefore, it is desirable for persons in affected families to obtain consultation at a designated HHT Center regarding the need for screening and treatment.

HHT Centers are willing to conduct some portions of the technical component of diagnostic tests within the patient's insurance provider network, with a professional component being conducted at the HHT Center. It is imperative the HHT Center providers define/order the screening tests according to specific protocol for detecting arteriovenous malformations. The consultation is most efficient if some screening tests are performed prior to, or simultaneous to the consult visit.

Please consider this out-of-network request for a consultation at (HHT Center name).

Thank you for your prompt consideration of this request.

Sincerely,

(Physician or patient making referral request)